



*Of the older persons receiving paid and unpaid assistance, 95 percent have family and friends involved in their care.*

*Paid home care is the exception, not the rule, for the great majority of older persons with disabilities.*

*The unanimous, resounding message delivered by hundreds of individuals who care for their older loved ones is: families need help.*

## Family Caregiving

Families, not social service agencies, nursing homes or government programs, are the mainstay underpinning long term care (LTC) for older persons in the United States. According to the most recent National Long Term Care Survey, more than seven million persons are informal caregivers – providing unpaid help to older persons who live in the community and have at least one limitation on their activities of daily living. These caregivers include spouses, adult children, and other relatives and friends.

The degree of caregiver involvement has remained fairly constant for more than a decade, bearing witness to the remarkable resilience of the American family in taking care of its older persons. This is despite increased geographic separation, greater numbers of women in the workforce, and other changes in family life. Thus, family caregiving has been a blessing in many respects. It has been a budget-saver to governments faced annually with the challenge of covering the health and long term care expenses of persons who are ill and have chronic disabilities. If the work of caregivers had to be replaced by paid home care staff, the estimated cost would be \$45-75 billion per year.

### Recognition of Caregivers

Recognition of the role of families in providing long term care is moving to the forefront of national policy making. For example, the Family and Medical Leave Act was signed into law in 1993 to ensure that businesses address the needs of their employees with regard to eldercare. Also, added emphasis has been placed on formally recognizing and honoring family caregivers. In 2000, November was designated as National Family Caregivers Month to further recognize the efforts of these unsung heroes, who dedicate themselves unselfishly, day-in and day-out, to caregiving.

### The National Family Caregiver Support Program

The enactment of the Older Americans Act Amendments of 2000 (Public Law 106-501) established an important new program, the National Family Caregiver Support Program (NFCSP). The program was developed by the Administration on Aging (AoA) of the U.S. Department of Health and Human Services (HHS). It was modeled in large part after successful state long term care programs in California, New Jersey, Wisconsin, Pennsylvania, and others, and after listening to the needs expressed by hundreds of family caregivers in discussions held across the country.



## ***Demands on Caregivers***

*Caregivers dedicate, on average, 20 hours per week to provide care for older persons and even more time when the older person has multiple disabilities.*

*Caring for an older person with disabilities can be physically demanding, particularly for older caregivers, who make up half of all caregivers.*

*One-third of all caregivers describe their own health as fair to poor.*

*Caregivers often indicate they are not sure they will "out-survive" the people for whom they are caring; thus, there are often two "at risk" persons in the making: the caregiver and the person cared for.*

*Because caregiving is such an emotionally draining experience, caregivers experience depression at three times the rate of others in their own age group, and they are more likely to fall physically ill.*

Funded at \$125 million in fiscal year 2001, approximately \$113 million has been allocated to states through a congressionally mandated formula that is based on a proportionate share of the population age 70 and older.

The program calls for all states, working in partnership with area agencies on aging and local community-service providers to have five basic services for family caregivers, including:

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to services;
- Individual counseling, organization of support groups, and caregiver training to caregivers to assist the caregivers in making decisions and solving problems relating to their caregiving roles;
- Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- Supplemental services, on a limited basis, to complement the care provided by caregivers.

In January, 2001, AoA issued guidance to states on the implementation of the new program, and on February 15, HHS Secretary Tommy G. Thompson announced the release of those funds to states. AoA is planning a technical assistance conference for the Fall. The conference will highlight innovative and successful state caregiver support initiatives that might warrant replication.

## **Eligible Populations**

- Family caregivers of older adults;
- Grandparents and relative caregivers, age 60 years or older, of children no older than age 18 (including grandparents who are sole caregivers of grandchildren and those individuals who are affected by mental retardation or who have developmental disabilities).

The statute requires states to give priority consideration to:

- Persons in greatest social and economic need (with particular attention to low-income, minority individuals); and
- Older individuals providing care and support to persons with mental retardation and related developmental disabilities.

## Other Important Features

The Native American Caregiver Support Program is established within the Older Americans Act Amendments of 2000. It is funded with \$5 million of the \$125 million designated to assist caregivers of Native American elders who are chronically ill or have disabilities. In addition, \$6 million of the \$125 million will be used to fund competitive innovative grants to further develop comprehensive and effective systems of support in family caregiving. AoA will issue a request for proposals in the Spring of 2001.

## Who to Contact for Help

The local AAA is one of the first resources a caregiver should contact when help is needed. Almost every state has one or more AAA, which serve local communities, older residents, and their families. (In a few states, the State Unit or Office on Aging serves as the AAA.) Local AAA's are generally listed in the city or county government sections of the telephone directory under "Aging" or "Social Services."

For more information on the implementation of the NFCSP in a particular state, contact the State Unit on Aging. Information on State Units on Aging is available at: [www.aoa.gov/aoa/pages/state.html](http://www.aoa.gov/aoa/pages/state.html).

## The Eldercare Locator

AoA supports a nationwide, toll-free information and assistance directory called the Eldercare Locator, 1-800-677-1116 which can find the appropriate AAA to help an individual seeking assistance for their loved ones, relatives, or friends. Eldercare Locator operators are available Monday through Friday, 9:00 a.m. to 8:00 p.m., Eastern Time. When contacting the Locator, callers should have the address, zip code, and county of residence for the person needing assistance.

**Working in close partnership with its sister agencies in the U.S. Department of Health and Human Services, the AoA is the official Federal agency dedicated to policy development, planning and the delivery of supportive home and community-based services to older persons and their caregivers. The AoA works through the national aging network of 57 State Units on Aging, 655 Area Agencies on Aging, 225 Tribal and Native organizations representing 300 American Indian and Alaska Native Tribal organizations, and two organizations serving Native Hawaiians, plus thousands of service providers, adult care centers, caregivers, and volunteers. For more information about the AoA, please contact:**

**U.S. Administration on Aging  
Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, DC 20201**

**Phone: (202) 619-0724  
Fax: (202) 260-1012  
Email: [aoainfo@aoa.gov](mailto:aoainfo@aoa.gov)  
Web: [www.aoa.gov](http://www.aoa.gov)**

**Eldercare Locator: 1-800-677-1116, Monday – Friday, 9 a.m. to 8 p.m. ET**